Emergency preparedness of families of children with developmental disabilities: What public health and safety emergency planners need to know

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Abstract

Objective—To assess the emergency preparedness knowledge, behaviors, and training needs of families of children with developmental disabilities (DD).

Design—An online survey.

Participants—A sample of 314 self-selecting US parents/guardians of children with DD, aged birth-21 years.

Main outcome measures—1) Preparedness self-assessment; 2) self-report regarding the extent to which families followed 11 specific preparedness action steps derived from publicly available preparedness guides; and 3) parent training and support needs.

Results—Although most participants assessed themselves to be somewhat to moderately well prepared, even those who reported being "very well prepared" had taken fewer than half of 11 recommended action steps. Most participants expressed a need for preparedness support; virtually all the respondents felt that training was either important or very important.

Conclusions—Children with disabilities are known to be particularly vulnerable to negative disaster impacts. Overall, parents in this study appeared under-prepared to meet family disaster

needs, although they recognized its importance. The results suggest opportunities and methods for public health and safety planning, education and outreach to parents of children with DD who would benefit from targeted training such as information and skill building to develop effective family preparedness plans and connections to local emergency management and responders.

Keywords

children; developmental disabilities; emergencies; disasters; functional and access needs; emergency planning; emergency preparedness

INTRODUCTION

All children remain vulnerable to the negative impacts of emergencies and disasters,[1] but children with developmental disabilities (DD) and special healthcare needs (SHCN) (who represent approximately 14.6 million children in the United States[2]) may face even greater risks.[3] Unfortunately, American emergency planning and response systems have historically ignored children's needs, often treating children as miniature adults without regard to their distinctive physiological and emotional characteristics.[4,5] Greater public attention focused on the issue of emergency planning for children after thousands of children experienced separation from their families, emotional trauma, and disrupted daily activities due to Hurricane Katrina in 2005.[6] Vigorous advocacy continued after the hurricane and led to the release of a national commission report in 2010.[1] The report called for increased attention to children's medical, mental health, social/emotional, and educational needs and integration of these issues into disaster planning, response and recovery, with enhanced capabilities and specific action steps to be taken by the President, Congress, and federal agencies.[1]

If all children are at risk from the negative impacts of emergencies, then children with disabilities may be particularly susceptible.[3,7,8] For example, research suggests that children with pre-existing chronic health conditions impacted by Hurricane Katrina experienced greater disruptions in care, sought care for new health problems more often, were more likely to develop secondary health problems, and developed more negative psychological symptoms than other children.[9] More than typically developing children, those with disabilities may have multiple medical conditions, specialized medication and diets, fragile adaptive equipment, follow specific schedules and have limited ability to quickly follow directions, take self-protective actions or communicate independently, any of which might lead to delays in receiving needed services during emergencies.[10–12] Children with disabilities may also require greater or different emergency services than typically developing children[8] and may pose additional challenges to the emergency response system,[3,12] straining resources.

Research confirms responder and emergency management knowledge gaps about the likely emergency needs of individuals with disabilities.[13,14] Baker and Baker[3] and Mace et al.[12] note the lack of disaster medical team training and Emergency Medical Service protocols to address children with SHCN. Yet under the Americans with Disabilities Act (ADA), Pub. L. No. 101–336, 104 Stat. 328 (1990), individuals with disabilities, including children with disabilities, are entitled to equal access to emergency services. The U.S. Department of

Justice Project Civic Access[15] has undertaken numerous compliance reviews of local and county emergency management plans and practice to ensure compliance with this mandate, which is also supported by Federal Emergency Management Agency guidance relating to "whole community" emergency planning.[16]

Families must also take responsibility for preparedness.[17] Numerous commentators have noted that parents of children with disabilities need to anticipate and plan for the many disruptions to their child's daily routines, supports and services that may occur because of power and utility interruptions, environmental and other changes caused by emergencies and disasters.[4,18–21] Major health organizations, such as the American Academy of Pediatrics, the Institute of Medicine, the Children's Health Fund, and the National Center for Disaster Preparedness, have reached consensus about the critical importance of advance planning to adequately address the emergency needs of all children, including those with disabilities.[22]

There is much research on the emergency preparedness of the general public,[11,23,24] including research that indicates that having a child in the household increases preparedness.[23,25] Shaw et al.[26] emphasized the critical role that family education plays in helping children understand preparedness and in informing family preparedness behavior. There is also research regarding the preparedness of adults with disabilities.[11,23,27] However, the preparedness of families who have children with disabilities appears to be under-studied.[28] Baker and Baker[3] found limited preparedness among parents of children with SHCN presenting at a hospital emergency department and outpatient clinic in Alabama, noting that the parents studied lacked knowledge of four of five emergency preparedness indicators. Baker and Cormier[29] found no difference in preparedness levels of Alabama and Florida parents of children with SHCN, suggesting no preparedness differences based on geography, but did find increases in preparedness after a brief educational intervention. In unpublished research, the Massachusetts Department of Public Health (MA DPH, Office of Family Initiatives, unpublished data, 2004–2006) found a large number of parents of children with SHCN unprepared for emergencies, uninformed about local emergency planning, and in need of training and support. A Florida survey conducted by Lou et al.[30] found that parents of preschool children with Autism Spectrum Disorder (ASD) were concerned about the impact of ASD on the family's ability to cope during hurricanes and were in need of further education.

In 2009, we developed an online survey to examine the emergency preparedness knowledge, behaviors, support, and training needs of US parents of children with disabilities in an attempt to contribute to the literature and to inform future parent education interventions. Research questions included the following: 1) How prepared do parents of children with disabilities feel to care for their children during an emergency? 2) How many specific recommended preparedness action steps do they report taking and, based on these steps, how prepared do these families appear to be? 3) Do parents indicate a need for emergency preparedness training or support? This article reviews the results of the survey and suggests opportunities and methods for public health and safety education, planning, and outreach to this population.

METHODS

We developed the online survey using SurveyMonkey®. E-mail invitations and a Web site hyperlink were sent to approximately 430 national and state disability and/or SHCN organizations with requests to distribute the survey to their affiliated organizations or directly to parents and guardians. Additionally, e-mail invitations were sent to six prominent Massachusetts parent opinion leaders who were asked to forward the e-mail invitation to their networks. Prior to dissemination, the survey was granted an exemption by the University of Massachusetts Medical School Institutional Review Board.

The survey queried respondents (parents and guardians) about the type(s) of disabilities or SHCN their children had and their children's ages. A child with a disability or SHCN was defined as having one or more of the following conditions: asthma or severe allergies; attention deficit/hyperactivity disorder (ADHD); ASD (including Pervasive Developmental Disorder Not Otherwise Specified [PDD-NOS], Autism, and Asperger's syndrome); cancer; a developmental disability or delay; epilepsy or a seizure disorder; genetic disorder; hearing or visual disability; intellectual disability; learning disability; physical disability; psychiatric disability; and speech or communication disability. We collapsed the diagnoses listed in the survey into four categories to focus more closely on families with children with DD or DD with a concomitant medical condition. Children reported to have an intellectual disability, a developmental disability or delay, and/or ASD were classified as having DD/ASD. Children with DD *plus* a physical and/or sensory (hearing or vision) disability were grouped in the physical disability/sensory disability (PS) category. Children with DD who also had a medical condition (which included asthma, cancer, diabetes, and/or a seizure disorder) were classified as having a medical disability (MD). Children with DD *and* MD plus a physical *and/or* sensory disability were classified as MDPS (ie, having a developmental and medical disability as well as a physical and/or sensory disability). Write-in diagnoses were coded into one of the four categories.

Parents were asked whether they had ever personally experienced a natural or human-caused disaster or emergency and to describe what they had experienced. Respondents were also asked to indicate on a five-point Likert-type scale how prepared they felt to respond to an emergency and to indicate whether they had taken any of a series of emergency preparedness action steps. These items were developed after a review of online and print guides aimed at the general population, adults with disabilities, parents of typically developing children, and children with disabilities/SHCN.[17,31–36] The steps included the following: making plans, stockpiling and/or gathering information, holding a family emergency preparedness discussion, developing a written emergency plan, practicing the emergency plan, developing an emergency medical information sheet, creating a written communication plan, having 72 hours' worth of supplies at home, having an evacuation plan and emergency supply bag for evacuation, providing information to a Special Needs Registry19[*] or 9-1-1 emergency telephone service, knowledge of a public emergency shelter

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[*]Special Needs Registries are paper or computer-based voluntary databases of information about individuals with disabilities/SHCN that some localities use for locating, communicating with and/or responding to people with disabilities during emergencies. Enhanced 9-1-1 refers to specialized features of Emergency 9-1-1 telephone service which enable a 9-1-1 dispatch operator to see on their computer screen limited disability or special healthcare need information from a household making a 9-1-1 telephone call.

location, and shelter accessibility. The survey also included questions about parents' familiarity with local emergency resources and whether they had interacted with those resources. They were also asked questions about disaster planning with their child's school. Finally, parents were asked to rate the importance of emergency preparedness planning for families of children with disabilities/SHCN and the specific topics which should be included in trainings. A total of 14 questions were asked.

Data analysis

Comparisons were made between and among the four groups of children with disabilities. Comparisons for categorical variables were compared using chisquare or Fisher's Exact Test (to account for small cell sizes) and continuous variables were compared via analysis of variance, with overall significant differences among groups analyzed post hoc using Tukey Honestly Significant Difference. A p value of less than 0.05 was used to determine statistical significance. Data were analyzed using SPSS Statistics for Windows, version 17 (SSPS, Inc., Chicago, IL) and Stata Data Analysis and Statistical Software, version 13 (StataCorp LP, College Station, TX).

RESULTS

A convenience sample of 449 parents or guardians of children from birth through age 21 with a disability or SHCN completed the survey. Forty-three respondents (n = 43) whose children had ADHD, a psychiatric disorder, a communication disorder, a learning disability, and/or a genetic disorder but did not have DD, were excluded, as were 12 respondents (n = 12) whose children's disabilities did not correspond to the aforementioned listed conditions. Respondents who indicated more than one child with a disability/SHCN and/or reported information about children older than 22 years (n = 117) were also excluded. These exclusions yielded a final sample of 314 participants. Table 1 shows the respondents' children categorized into groups based on disability and co-occurring conditions. The age difference among the children was not statistically significant.

Experiencing an emergency or disaster

More than a third of the participants (37 percent) reported personally experiencing an emergency, such as weather-related emergencies (eg, blizzard, hurricane, ice storm, and tornadoes), other natural disasters (eg, earthquake, flood, and wildfire), or human-caused disasters (eg, chemical spill or terror attack). A number of respondents commented on the disruption to their child's daily life caused by these events. For example, one parent of a child with ASD wrote the following:

> "There was a[n]… ice storm…the power [was] out for 5 days…[and] we did not have any heat. It was difficult to take our daughter to live elsewhere… .She had a difficult time being in the hotel room because… she is used to a strict routine, [we had to] live in 'tight' quarters—all of us were in [one] room, [she wasn't] able to sleep in her own room… in her own bed which is a [hospital] bed … .Because she was taken out of her home she did not eat[] or sleep well and…had issues going to the bathroom."

Level of emergency preparedness

Most respondents assessed themselves to be at a slightly less than moderate level of emergency preparedness (mean of 2.7 (1.1)) on a five-point Likert-type scale with 1 being "very unprepared" and 5 being "very prepared." There were no significant differences found among the four groups. Table 2 shows respondent self-assessment of emergency preparedness level based on this scale.

Table 3 lists the 11 preparedness indicators ranked from most frequently to least frequently taken. Nearly half of respondents (48 percent) reported holding family discussions about emergency planning, and less than half (43 percent) reported having assembled 72 hours worth of emergency supplies. Slightly more than one third of respondents (37 percent) reported knowing where at least one emergency shelter was located in their town, while slightly less than one third (31 percent) knew whether that shelter was accessible. A little over one third of the participants (35 percent) reported having written emergency medical information for their child. The majority (69 percent) reported not having any evacuation plans, with an even larger number (86 percent) reporting they lacked an evacuation supply bag. Almost 15 percent of respondents reported sharing information about their child's emergency needs with a Special Needs Registry or emergency 9-1-1 telephone service database. Only 9 percent reported having a written communication plan and 5 percent reported having a written emergency plan. The vast majority of parents (91 percent) reported not having practiced an emergency plan.

We found no significant difference among the four groups regarding most of the action steps taken; however, as shown in Table 3, there was a statistically significant difference in maintaining emergency medical information ($p < 0.001$) and evacuation bags ($p = 0.005$) among the participants. Nearly two thirds of families (62 percent) whose children were in the MDPS group reported having an emergency medical information sheet. In contrast, 23 percent of families with children with DD/ASD, 48 percent with children with DD and physical and/or sensory disabilities (PS), and 39 percent of those whose child had a medical condition (MD) reported having a completed emergency information sheet for their child. Additionally, 27 percent of families with a child in the MDPS group and 22 percent of families with a child in the MD group reported having an evacuation bag compared to the other two groups (10 percent for both DD/ASD and PS groups).

Overall, respondents reported taking far fewer than the 11 preparedness steps. The average number of preparedness action steps a respondent reported corresponded with their preparedness self-assessment. For example, those who assessed themselves to be "Very unprepared," reported taking an average of 1.2 preparedness steps while those who considered themselves "Very prepared" reported taking an average of 4.7 potential preparedness steps on a five-point scale. Table 4 illustrates the number of action steps taken by self-assessed preparedness level.

Post hoc analysis (Tukey Honestly Significant Difference) suggested significant differences among some of the different self-assessed preparedness levels. Those who rated themselves at a moderate level (preparedness level 3) took significantly more preparedness steps than did those rating themselves at levels 1 and 2 ($p < 0.001$). Those who assessed themselves as

more prepared (levels 4 and 5) took significantly more preparedness steps than did those rating themselves at the lowest preparedness level, level 1 ($p < 0.001$ for both levels 4 and 5), level 2 ($p < 0.001$ for both levels 4 and 5), or level 3 ($p = 0.013$ for level 4 and $p = 0.041$ for level 5). There were no significant differences between those respondents rating themselves at preparedness level 1 and those rating themselves at level 2 ($p = 0.496$), nor was there a significant difference between those who rated themselves at level 4 and those who rated themselves at level 5 ($p = 0.970$).

Knowledge of community-related emergency planning and resources

We asked participants about their familiarity with disaster or emergency resources for children with disabilities in their community as well as their use of Special Needs Registries. A very small minority (4 percent) of parents reported being familiar or very familiar with these resources and 65 percent indicated no familiarity at all. Approximately 15 percent of parents reported sharing information about their child with an emergency registry or with emergency 9-1-1 services.

As children with disabilities spend much of their day at school or with care or service providers, respondents were surveyed about emergency planning conversations with these entities. Slightly more than one third of parents (36 percent) reported having had a conversation about whether their child's school had an emergency/disaster plan. Of those parents who had this conversation, 48 percent reported that the school had made special provisions for their child, 18 percent reported that no special provisions had been made for their child, and 33 percent reported not knowing whether the school had made any special provisions. A small percentage of respondents (14 percent) reported speaking with their child's care or service providers about a written emergency plan. Of those, 41 percent reported that the service provider had a specific plan to continue their child's services during an emergency, while 16 percent reported that there was no specific plan to continue providing their child's care. Forty-two percent of respondents who reported having had such a conversation did not know whether the service provider had a specific plan for continuing their child's care during an emergency. Table 5 illustrates parent familiarity and coordination efforts with local emergency services and resources.

Training and support needs

The parents surveyed indicated a strong need for training and support to develop a family emergency plan, with 86 percent of respondents rating such training as being "important" or "very important." In addition, most respondents indicated a need for additional training or supports such as speaking with an expert, help recording or implementing their emergency plan, and speaking with emergency responders in advance of an emergency. Slightly less than half (46 percent) felt visiting a shelter was important.

In terms of training format, the large majority of respondents identified online or computer training, in combination with in-person training, as their preferred learning format. Table 6 illustrates respondent interest in training and other supports.

DISCUSSION

Our goal was to assess the emergency preparedness of parents of children with DD, whether parents felt a need for preparedness training or support, and whether levels of preparedness differed among families whose children had DD and co-occurring conditions. Our results indicate that like much of the general public,[3] parents of children with DD were under-prepared for emergencies, both by self-report of their general state of preparedness and by number of preparedness steps taken. These findings are consistent with those of Baker and colleagues,[3,37] who found that parents of children with SHCN were generally unprepared in terms of supplies, planning, and knowledge. Baker and colleagues' findings suggest no differences in preparedness levels between parents whose children had a single special need and those whose children had more than one special need. Our findings are to the contrary; we found significant differences relating to the number of parents having written emergency information and an evacuation bag. Parents of children with the greatest needs, that is, children with developmental, medical, and sensory/ physical conditions (MDPS), were more prepared than families of children with fewer co-occurring conditions, based on our list of preparedness steps.

The vast majority of our survey participants felt that preparedness education was important or very important. The need for family education is supported by Shaw et al.[26] and by Baker and Baker's[3] work and is consistent with the studies mentioned earlier.

Our study sought information about parents' preferred training format. Fifteen percent of parents we surveyed preferred in-person training, approximately 21 percent preferred computer or online training, and 63 percent preferred a combination of computer or online plus in-person training. The importance of parent-to-parent mutual support has long been recognized in the disability community.[38] Perhaps the strong interest in having at least one in-person session found in both our study and the study by Lou et al.[30] reflects an interest in connecting with other similarly situated parents for mutual support regarding emergency planning.

There are a number of limitations to this study. The sample was a convenience sample, limited to those with access to a computer and online network, computer skills, and ability to read and respond in English. Thus, the survey did not likely reach parents who lacked a computer or Internet access or those with limited English proficiency. The sample was largely represented by Massachusetts parents (approximately 40.4 percent, n = 127), thereby making the survey potentially less representative of the country as a whole. Additionally, the study did not evaluate the nature or quality of specific preparedness action steps (eg, the kind of information included in an emergency medical information sheet or optimum supplies for an evacuation bag) or examine the nature of contingency planning related to specific children or specific conditions (eg, plans for alternate mobility if a power wheelchair were unavailable). Since this study was completed in 2009, as described above, there have been only a few other studies related to parents of children with disabilities. As the American public generally becomes better educated and perhaps more prepared for emergencies, parents of children with disabilities might also become more prepared and future studies might examine this issue.

Despite these limitations, we found that the families of children with DD surveyed were generally not well prepared for the potential negative impacts to their children from emergencies or disasters. Our data also suggest that parents of children with disabilities would benefit from targeted training to increase knowledge and skills to develop an effective family emergency plan. This research contributes to the literature in an under-studied field, suggests the need for preparedness education, and is of importance to emergency management and public health professionals for reasons of legal compliance and emergency response efficiency. Equal access to emergency services is mandated under the ADA and, as children with disabilities may have greater or different emergency service needs than other children,[8] advance planning by their families and local emergency management may decrease the resources and response effort that would be needed to meet their needs during an actual emergency, thereby promoting greater response efficiency. Local emergency planners might also use education and planning efforts as opportunities to encourage stakeholder participation by inviting parents of children with disabilities to become involved in community emergency planning efforts.

In addition to informing training format, the results reported here can be used to inform training content. Such content could include the following: 1) an understanding of local emergency resources; 2) strategies for discussions with schools and service providers; 3) help developing and recording family emergency plans (perhaps via a plan template) with a focus on planning for the specific needs of individual children; 4) strategies for approaching local emergency officials to discuss family needs; and 5) visiting a local shelter site. Our data suggest that only 15 percent of respondent parents had used a Special Needs Registry or emergency telephone 9-1-1 database to share information about their child. While there is limited evidence of registry effectiveness and some controversy related to privacy and other concerns,[19] a number of localities make these forms available. Training content that included a discussion of the pros and cons of registries, and a description of the privacy protections built into the local registry, might also be beneficial to parents. Finally, our results indicate that parents feel they would benefit from assistance recording their family's emergency plan; perhaps training sessions might include time for parents to record family plans with assistance from the trainer as needed.

Reaching out to parents of children with disabilities may be a challenge for emergency response personnel. One way to connect with parents might be via local or statewide advocacy, education or social service provider organizations (see Table A1 in Appendix A for a resource list). While these organizations are unlikely to be willing to share names and contact information due to privacy concerns, the organizations might serve as conduits, sharing general and aggregate information about this population with local planners, managers and responders, forwarding preparedness education resources to constituent families, hosting parent preparedness trainings, and serving as useful community emergency planning partners.

This study focused on families challenged by having a child with a developmental delay, developmental or intellectual disability and/or autism, with and without additional conditions. There are indications of differences in preparedness behaviors among parents whose children have DD/ASD and those whose children have DD with co-occurring

medical conditions. Additional research might further examine these differences, to better identify whether the greater number or more complex nature of a child's disability leads to different or greater parent preparedness levels, training, and support needs. Other research might focus on families whose children have disabilities or SHCN other than DD, such as learning disabilities or cancer. An assessment of potential barriers to preparedness faced by families challenged by disability would also be important.

Children with disabilities are among our most vulnerable community members. As primary caregivers, it is critical that parents have the resources and support they need to successfully create and implement family emergency plans; it is equally important that public health and safety emergency personnel provide the education and support these parents need to develop family plans, while incorporating the needs of these families into "whole community" community-wide inclusive emergency planning efforts.

ACKNOWLEDGMENTS

APPENDIX A

OUTREACH TO FAMILIES OF CHILDREN WITH DISABILITIES/SPECIAL HEALTHCARE NEEDS

Disability-related organizations for potential preparedness education efforts are given in Table A1.

Table A1

Disability-related organizations for potential preparedness education efforts

Organization/agency name	Description	Preparedness education and planning opportunities	Contact information
Local organizations			
Public school system	City, town, or county public school system special education or pupil services department and/or special education parent council or other similar group	Special education parent councils often host training sessions, which would provide an opportunity for parent education. School systems may be able to share aggregate information (without student names) that might be useful for local planning purposes	Contact the local school system
Americans with Disabilities Act (ADA) co-ordinator or Disability Commission	City, town, or county ADA compliance officials or a local Disability Commission	These groups may be able to foster connections to local disability service providers or advocacy groups or be willing to	Contact city, town, or county offices

Organization/agency name	Description	Preparedness education and planning opportunities	Contact information
		host a preparedness training	
State organizations			
Family Voices	National network of state organizations promoting family-centered care for children with disabilities/ SHCN	State Family Voices groups may be interested in preparedness presentations at conferences, may be able to serve as a conduit to local or state disability provider or advocacy organizations, or be willing to share preparedness information with member parents, for example via e-mail or the Internet	Go to http://www.familyvoices.org/ to find a state's Family Voices group
Parent to Parent (P2P)	Many states have parent led "parent to parent" mutual support groups	State P2P groups may be interested in preparedness presentations at conferences, may be willing to serve as a conduit to local or state disability provider or advocacy organizations, or be willing to share information with member parents, for example via e-mail or the Internet	Go to http://www.p2pusa.org/p2pusa/SitePages/p2p–support.aspx to find a state's Parent to Parent group(s)
Parent Training and Information Centers (PTIs)	Each state has one or more PTIs for parents of children with disabilities	PTIs may have regional or statewide trainings at which emergency managers might speak or share information and resources. Information might also be shared via the PTI Web site	Go to http://www.parentcenternetwork.org/parentcenterlisting.html to find a state's PTI
University Centers of Excellence in Developmental (and related) Disabilities (UCEDD) and Leadership Education in Neurodevelopmental (and related) Disabilities (LEND) programs	Many states have university-affiliated UCEDD research centers and/or LEND inter-disciplinary training programs with strong expertise related to the health and well-being of children and adults with developmental and other disabilities	UCEDDs and LENDs may be able to foster connections to disability provider or advocacy organizations; have an interest in conducting relevant research; or host public preparedness education programs. LEND trainees (students) might be interested in developing emergency preparedness education or dissemination projects	Go to the following links to find a state's LEND or UCEDD program(s): LEND: http://www.aucd.org/directory/directory.cfm?program=LEND UCEDD: http://www.aucd.org/directory/directory.cfm?program=UCEDD

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Table 1

Child disability status and age

Disability category	Description	N	Mean (SD) age, y
Developmental disability (DD/ASD)	Developmental disability, developmental delay, intellectual disability, and/or Autism Spectrum Disorder (ASD)	176[*]	10.8 (5.3)
DD and physical disability and/or sensory disability (PS)	Developmental disability, developmental delay, intellectual disability and/or ASD plus physical disability and/or sensory disability (hearing or vision impairment)	41	10.7 (5.7)
DD and medical disability (MD)	Developmental disability, developmental delay, intellectual disability and/or ASD plus medical condition (cancer, asthma, diabetes, seizure disorder)	41	13.0 (4.1)
DD and MD, physical disability and/or sensory disability (MDPS)	Developmental disability, developmental delay, intellectual disability and/or ASD plus MD plus physical disability and/or sensory disability	55	11.7 (5.0)
Total		314	11.2 (5.2)

[*] One respondent did not specify an age.

Table 2

Self-reported preparedness level

	N (percent)
1. Very unprepared	46 (15)
2.	81 (26)
3.	122 (39)
4.	46 (15)
5. Very prepared	16 (5)
Total	311 (100)

Table 3

Rank order and significance of reported preparedness action steps taken (N = 314)[*]

Rank order	Emergency preparedness steps taken/specific knowledge	N (percent) (reporting yes)	p value
1	Family discussion: overall	150 (48)	0.718
	DD/ASD	83 (47)	
	PS	19 (46)	
	MD	18 (44)	
	MDPS	30 (54)	
2	72 h worth of emergency supplies for the house: overall	133 (43)	0.630
	DD/ASD	77 (44)	
	PS	14 (34)	
	MD	17 (41)	
	MDPS	25 (47)	
3	Know location of at least one shelter: overall	112 (37)	0.317
	DD/ASD	70 (41)	
	PS	11 (28)	
	MD	12 (30)	
	MDPS	19 (35)	
4	Emergency medical information sheet: overall	109 (35)	<0.001
	DD/ASD	40 (23)	
	PS	19 (48)	
	MD	16 (39)	
	MDPS	23 (62)	
5	Know whether shelter is accessible: overall	92 (31)	0.268
	DD/ASD	58 (35)	
	PS	7 (19)	
	MD	11 (28)	
	MDPS	16 (29)	
6	Evacuation plan: overall	96 (31)	0.280
	DD/ASD	51 (29)	
	PS	15 (37)	
	MD	9 (22)	
	MDPS	21 (38)	
7	Used registry/enhanced 911: overall	46 (15)	0.151[†]
	DD/ASD	23 (13)	
	PS	9 (23)	
	MD	3 (8)	
	MDPS	11 (20)	

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Rank order	Emergency preparedness steps taken/specific knowledge	N (percent) (reporting yes)	p value
8	Evacuation bag: overall	45 (14)	0.005[†]
	DD/ASD	17 (10)	
	PS	4 (10)	
	MD	9 (22)	
	MDPS	15 (27)	
9	Written communication plan: overall	29 (9)	0.794[†]
	DD/ASD	15 (9)	
	PS	3 (8)	
	MD	5 (13)	
	MDPS	6 (11)	
10	Practiced family emergency plan: overall	27 (9)	1.000[†]
	DD/ASD	16 (9)	
	PS	3 (7)	
	MD	3 (7)	
	MDPS	5 (9)	
11	Written family emergency plan: overall	16 (5)	0.522[†]
	DD/ASD	8 (5)	
	PS	2 (5)	
	MD	4 (10)	
	MDPS	2 (4)	

[*]Sample size varied by question.

[†]Fisher's Exact Test.

Table 4

Number of action steps taken by preparedness level

Self-reported preparedness level	Mean number of action steps taken (SD)	N (percent) (total n = 281*)
1. Very unprepared	1.2 (1.3)	41 (15)
2.	1.8 (1.5)	69 (25.0)
3.	3.2 (2.0)	115 (41)
4.	4.3 (2.5)	41 (15)
5. Very prepared	4.7 (2.8)	15 (5)

*Thirty-three respondents excluded due to missing responses.

Table 5

Familiarity and coordination efforts with community emergency planning and resources

	N (percent)	Total N
Respondents indicating being familiar or very familiar with community emergency services (4 or 5 on a five-point scale)	14 (4)	312
Respondents indicating "Yes" to sharing/planning with emergency resources		
Shared child's information with a Special Needs Registry	46 (15)	312
Emergency planning discussion with school	112 (36)	311
If discussion held, school has emergency plan for child	54 (48)	112
Emergency planning discussion with service provider	39 (14)	289
If the provider has disaster plan, is there a specific plan for the child during a disaster/emergency?		
Yes	18 (41)	44
No	7 (16)	
Don't know	19 (42)	

Table 6

Emergency preparedness training and support needs

	N (percent)	Total N
Number (percent) of parents rating training as important or very important (4 or 5 on a five-point scale)	259 (86)	301
Number (percent) of parents indicating the following training /support needs being important or very important (4 or 5 on a five-point scale)		
Talking with an expert about making a specific emergency plan for the family	187 (63)	297
Getting help recording the emergency plan on paper or computer	160 (54)	299
Getting help implementing the plan	173 (59)	295
Visiting an emergency shelter	134 (46)	294
Advance meeting with emergency management officials (fire, police or other first responders)	186 (63)	293
Preferred format for training		295
In-person workshop	44 (15)	
CD-ROM or DVD	16 (5)	
Online (using the computer)	48 (16)	
Combination of online and in-person training	187 (63)	